

Cancer Survivorship Websites and Resources

DENICE ECONOMOU, RN, MN, CHPN, MARCIA GRANT, RN, DNSc, and MARY McCABE, RN, MA

As cancer treatment continues to improve and our strategies to prevent and detect new cancers develop, the number of survivors will continue to grow. As statistics show, these patients will number over 11 million by 2020 (National Cancer Institute [NCI], 2011). As the population of cancer survivors continues to grow, awareness of available resources is essential. Advanced practitioners (APs) are the primary coordinators of follow-up care for these patients. Helping patients and their families navigate the available survivorship resources is an important component of the support APs can provide.

Cancer survivors and their families deal with multiple long-term symptoms and late effects that may affect them throughout the rest of their lives. The Institute of Medicine (IOM) consensus report *From Cancer Patient to Cancer Survivor—Lost in Transition* provides a framework of the essential elements of survivorship care (IOM, 2006). The main components for success include coordination and communication, prevention, surveillance for secondary cancers and recurrence, and management of side effects related to treatment or

the disease. Multiple resources are available to provide support to cancer survivors and their families (Table 1).

Coordination and Communication

Resources for coordination and communication in cancer survivorship care include treatment summaries and survivorship care plans. The Commission on Cancer through the American College of Surgeons will require a treatment summary to be provided to all cancer patients by 2015 (American College of Surgeons & Commission on Cancer, 2012).

Some advanced practitioners and physicians are currently providing these plans for patients, but a coordinated multidisciplinary group effort is needed to achieve widespread implementation. As electronic medical records become more prevalent, treatment summaries will be much easier to complete. Unfortunately, electronic medical records are not widespread as of yet, and although it is essential, abstracting the treatment information from the medical record is very time consuming.

There are several websites that can assist patients in creating individualized survivorship

care plans. These can be completed by the patient and/or by a professional. Journey Forward (www.journeyforward.com), a program that was developed collaboratively with the National Coalition for Cancer Survivorship, UCLA Cancer Survivorship Center, the Oncology Nursing Society, WellPoint, Inc., and Genentech, is one such resource. Journey Forward's survivorship care plan builder, which can be accessed through the Internet, helps build a care plan that includes background information, treatment plan and summary, and follow-up care suggestions based on American Society of Clinical Oncology (ASCO) recommendations (Journey Forward, 2012). The **LIVESTRONG** Care Plan is another website-based care plan builder that has been updated using the OncoLink format with the University of Pennsylvania. Both of these resources offer patient educational materials as well as care plan follow-up recommendations.

A recognized key to success in care planning is beginning at diagnosis. These tools can be started as treatment begins and built upon throughout the treatment course. Encourage patients to keep a diary of treatments, and help your set-

Table 1. Cancer Survivorship Resources

Organization/Institute	Website	Focus
<i>Care Coordination/Communication</i>		
Journey Forward	www.journeyforward.org	Survivorship care plan template
LIVESTRONG Care Plan	www.livestrongcareplan.org	Survivorship care plan template
<i>Surveillance/Detection</i>		
American Cancer Society	www.cancer.org	Cancer survivor network
American Society of Clinical Oncology	www.cancer.net/patient/survivorship	Cancer survivorship booklet
National Comprehensive Cancer Network	www.nccn.com	Patient-friendly versions of NCCN Guidelines
<i>Quality-of-Life Interventions: Physical</i>		
American Cancer Society Cancer Survivors Network	csn.cancer.org	National cancer survivors resource center
Caring Ambassadors, Lung Cancer	www.lungcancercap.org	Lung cancer focused physical and social support
Centers for Disease Control and Prevention	www.cdc.gov/cancer/survivorship	Professional support resources
City of Hope Pain & Palliative Care Resource Center	prc.coh.org/	Professional resources focused on specific populations
Fertile Hope	www.fertilehope.org/	Professional and patient resources for fertility and parenting
National Cancer Institute, Cancer Survivorship Research	healthcare-professionals/index.cfm dcpns.nci.nih.gov/ocs	Professional and patient education tools, Facing Forward series
<i>Quality-of-Life Interventions: Psychological</i>		
Association of Cancer Online Resources	www.acor.org	Patient focused
Camp Mak-A-Dream	www.campdream.org	Children, adolescents, and young adults
Cancer Care	www.cancercare.org	Patient focused
Cancer Control P.L.A.N.E.T.	cancercontrolplanet.cancer.gov/	Research-tested resources for psychological screening, professional focused
Cancer.net survivorship area	www.cancer.net/patient/survivorship	Patient and professional support information
Cancer Support Community (formerly The Wellness Community and Gilda's Club Worldwide)	www.thewellnesscommunity.org	Patient support workshops and information
City of Hope Pain & Palliative Care Resource Center	prc.coh.org/qual_life.asp	Survivorship-specific materials
Cure Magazine, survivorship section	www.curetoday.com/index.cfm/fuseaction/journey.Survivorship/id/57	General information focused on patients' needs
Leukemia & Lymphoma Society	www.lls.org	Patient and professional support resources
Lymphoma Research Foundation	www.lymphoma.org	Patient-focused resources
Memorial Sloan-Kettering Cancer Center	www.mskcc.org/livingbeyoncancer	Patient support and newsletter, research resource
Memorial Sloan-Kettering Cancer Center, iTunes Survivorship Podcasts	itunes.apple.com/us/podcast/memorial-sloan-kettering-cancer/id429674197	Patient support and education podcasts
National Coalition for Cancer Survivorship	www.canceradvocacy.org	Patient and professional education
OncoNursing.com	www.onconursing.com	Patient education handouts

Continued on page 172

Table 1. Cancer Survivorship Resources (cont.)

Organization/Institute	Website	Focus
<i>Quality-of-Life Interventions: Psychological</i> Oncology Nursing Society	www.ons.org/CNEcentral/conferences/survivorship	Conference series
Patient Resource Publishing	www.patientresource.net	Patient education tools
Planet Cancer	www.planetcancer.org	Young adult resource
ACS Cancer Survivors Network: Steps for Living	csn.cancer.org/node/161327	Survivor-led consumer advocacy group
The SAMFund for Young Adult Survivors of Cancer	www.thesamfund.org	Young adults
The Ulman Cancer Fund for Young Adults	www.ulmanfund.org	Young adults
Young Adult Cancer Canada	www.youngadultcancer.ca	Young adults
Young Survival Coalition	www.youngsurvival.org	Adolescent and young adult resources
<i>Quality-of-Life Interventions: Social</i> Association of Oncology Social Work Cancer and Careers	www.aosw.org www.cancerandcareers.org	Professional support Advice, tools, and education events related to thriving in the workplace
Cancer Legal Resource Center	www.disabilityrightslegalcenter.org/about/cancerlegalresource.cfm	Legal support
Cancervive	www.cancervive.org	Patient and caregiver focus
City of Hope Pain & Palliative Care Resource Center	prc.coh.org/ethical-legal.asp	Ethical and legal materials
First Descents (Colorado)	www.firstdescents.org	Age 18-39 outdoor adventures
LIVESTRONG for Health Care Professionals	www.livestrong.org	Materials, partnerships, and tools to help health-care professionals support patients
Legal Health	www.legalhealth.org	Support for patients and caregivers
LifeLabs NewYork	www.lifelabsnewyork.com	Social ideas for living wisely and well
The Minnie Pearl Cancer Foundation	www.minniepearl.org	Patient and family support resources
Patient Advocate Foundation	www.patientadvocate.org/resources.php?p=14	Patient advocacy information, insurance and health-care access
SuperSibs	www.supersibs.org	Brothers and sisters of cancer survivors
<i>Quality-of-Life Interventions: Spiritual</i> City of Hope Pain & Palliative Care Resource Center George Washington Institute for Spirituality & Health	prc.coh.org/spirituality.asp www.gwumc.edu/gwish/soerce	Spirituality materials Educational and clinical resources in spirituality, religion, and health
<i>Blogs</i> Pearlman Cancer Center Survivorship Forum Living Her Purpose Vital Options International, Inc.	survivorshipforum.blogspot.com/2009/07/pearlman-cancer-center.html www.livingherpurpose.com www.vitaloptions.org	Developing survivorship programs Social blog for women with cancer Global cancer dialog

ting provide proactive treatment summaries to patients as they begin treatment. These steps will improve health-care providers' ability to coordinate follow-up care.

Surveillance, Detection, and Risk Reduction

Resources related to surveillance for new cancers and detection of recurrence are primarily based on the American Cancer Society guidelines for cancer screening. Surveillance protocols after a cancer diagnosis vary among some tumor sites with known recurrence risks, such as breast and prostate cancers. No standardized guidelines exist at this time, so follow-up surveillance is based on American Cancer Society, ASCO, and National Comprehensive Cancer Network (NCCN) recommendations for detection, prevention, and risk reduction. The NCCN provides guidelines in these areas for certain cancers, including breast, cervical, colorectal, lung, and prostate, as well as for genetic/familial high-risk assessment for breast and ovarian cancers (NCCN, 2012). Individual physicians may direct their patients' follow-up surveillance as desired.

Interventions

Resources for interventions are organized around the quality-of-life model for a can-

cer survivor, which includes physical, psychological, social, and spiritual domains. The City of Hope Pain & Palliative Care Resource Center (PRC) provides many resource publications, tools, and websites for cancer survivorship as well as pain, palliative care, and spiritual resources (City of Hope PRC, 2012). The NCI website <http://dccps.nci.nih.gov/ocs/> includes research resources as well as educational tools. Psychological and social resources offer access to professional as well as peer support.

Finally, there are growing numbers of blogs and other Internet resources for patient and caregiver support. The Pearlman Cancer Center blog was developed to help connect survivorship programs and share program-building resources and ideas. Many cancer survivors are very Internet-literate and use the Internet to connect to their peers. Memorial Sloan-Kettering Cancer Center's website includes a newsletter written by its survivors. It is an example of how survivors with professional experience can use their talents to reach out to other survivors.

Conclusions

The growing survivor population will continue to require AP support as the general population ages. Cancer survivors with multiple comorbidities need care and guidance. Inte-

grating survivorship care from diagnosis through treatment and follow-up can lead to quality cancer care for patients and their families.

Ms. Economou is Project Director/Senior Research Nurse Specialist at City of Hope, Duarte, California; Dr. Grant is Director of Nursing Research and Education in the Department of Population Sciences at City of Hope, Duarte, California; and Ms. McCabe is Director of the Cancer Survivorship Program at Memorial Sloan-Kettering Cancer Center, New York, New York.

REFERENCES

- American College of Surgeons & Commission on Cancer. (2012). Cancer program standards 2012: Ensuring patient-centered care. Retrieved from <http://www.facs.org/cancer/coc/cocprogramstandards2012.pdf>
- City of Hope Pain & Palliative Care Resource Center. (2012). *Survivorship*. Retrieved from <http://prc.coh.org>
- Institute of Medicine [IOM]. (2006). *From cancer patient to cancer survivor—Lost in transition*. In M. Hewitt, S. Greenfield, & E. Stovall (Eds.). Washington, DC: The National Academies Press.
- Journey Forward. (2012). Survivorship care plan builder 3.0. Retrieved from www.journeyforward.org
- National Cancer Institute. (2011). US cancer survivors grow to nearly 12 million. Retrieved from <http://www.cancer.gov/newscenter/pressreleases/2011/survivorshipMMWR2011>
- NCCN. (2012). National Comprehensive Cancer Network Guidelines for detection, prevention & risk reduction. Retrieved from http://www.nccn.org/professionals/physician_gls/f_guidelines.asp#detection